
Citation:

Southby, K (2016) Barriers to non-residential respite care for adults with moderate to complex needs: A UK perspective. Journal of Intellectual Disabilities. ISSN 1744-6309 DOI: <https://doi.org/10.1177/1744629516658577>

Link to Leeds Beckett Repository record:

<https://eprints.leedsbeckett.ac.uk/id/eprint/2937/>

Document Version:

Article (Accepted Version)

The aim of the Leeds Beckett Repository is to provide open access to our research, as required by funder policies and permitted by publishers and copyright law.

The Leeds Beckett repository holds a wide range of publications, each of which has been checked for copyright and the relevant embargo period has been applied by the Research Services team.

We operate on a standard take-down policy. If you are the author or publisher of an output and you would like it removed from the repository, please [contact us](#) and we will investigate on a case-by-case basis.

Each thesis in the repository has been cleared where necessary by the author for third party copyright. If you would like a thesis to be removed from the repository or believe there is an issue with copyright, please contact us on openaccess@leedsbeckett.ac.uk and we will investigate on a case-by-case basis.

Barriers to non-residential respite care for adults with moderate to complex needs: A UK perspective

Dr. Kris Southby, Centre for Health Promotion Research, Leeds Beckett University

Abstract

Respite aims to alleviate the stress and burden of caring for someone with an intellectual disability and/or autism. Respite can take place in a number of different ways, but most commonly occurs in a residential setting. Based on survey and interview data with carers, service users and stakeholders in a northern city in England, this paper explores some of the perceived or actual barriers to availing 'non-residential' respite. A number of barriers to non-residential respite are identified. Residential respite appears to be the default conceptualisation of 'respite' for carers, service users and stakeholders. Persuading carers, service, users and stakeholders to give up the familiarity and safety of residential respite in favour of a non-residential alternative will be challenging unless those involved are more informed. Limitations and directions for future research are suggested.

Key words

Carers, support services, respite, residential care

Introduction

Caring for someone with an intellectual disability and/or autism with moderate to complex needs can be stressful for parents and carers (Redmond and Richardson, 2003; Nankervis et al., 2011). Respite services exist to alleviate such stress and burden by providing a “temporary relief service” from the demands of continual caregiving (Cotterill et al., 1997; Mac Donald et al., 2007; Upshur, 1983: :13; Wilkie and Barr, 2008). In doing so, respite intends to provide carers a sense of renewal and confidence to continue caring; “a lifeline to [carers]...giving them the time and space to recharge their batteries” (Wilkie and Barr, 2008: :30). In the right circumstances respite care can also benefit service users, encouraging the development of independence, facilitate a wide range of social opportunities, and offer the chance to become more involved in the community (Wilkie and Barr, 2008; Nankervis et al., 2011). If delivered inappropriately, however, respite can have little effect on relieving carers’ stress and burden (Cotterill et al., 1997). Moreover, respite should not be used to sustain placement at home which is inappropriate (McGrotherp et al., 1993). There can also be tensions between carers and service users with respect to respite where a conflict of interest may emerge.

Respite can be considered to be any activity in which the cared for person is supported for a pre-arranged, short period of time by someone other than their usual family carer(s) (Nankervis et al., 2011). This can include day-trips, short-breaks, leisure activities, and overnight stays in community settings (Caples and Sweeney, 2011; Cotterill et al., 1997), as well as overnight stays in residential accommodation more traditionally associated with respite. ‘Person centred planning’ discourses advocate that

respite should be tailored to the needs of service users, not the state, and be delivered with a commitment to the family (Petr and Barney, 1991; Truesdale-Kennedy et al., 2006; Wilkie and Barr, 2008; HM Government, 2008; Mansell and Wilson, 2010). More emphasis on addressing individual family and service user need through “adopting a needs-led philosophy” in the delivery of respite is promoted as central to meeting the needs of families (Wodehouse and McGill, 2009; Truesdale-Kennedy et al., 2006) and delivering more cost effective services (Cotterill et al., 1997: :785; McConkey et al., 2011b). ‘Consumer directed care’ – in which service users and carers control their own care budget and make choices about the services they access, including who will deliver the services and when – has arisen as part of the drive to give service users and carers more choice and flexibility in respite (Redmond and Richardson, 2003). However, despite parents’ and carers’ desire for, and supposed availability of, more flexible and personalised provision (Cotterill et al., 1997; Wilkie and Barr, 2008), service users staying overnight in a residential facility – ‘residential respite’ – remains the most well-known and utilised form of respite in the UK (McConkey et al., 2011b). Given the ever greater survival rates of children born with intellectual impairments, the increasing lifespans of adults with intellectual impairments, and a decline in institutionalisation – not to mention recent austerity cuts to UK public services – an increasing demand is placed on such services (Caples and Sweeney, 2011; Nankervis et al., 2011).

The aim of the paper is to describe the actual or perceived barriers to availing non-residential respite for adults with an intellectual disability and/or autism with moderate

to complex needs in one northern city in England. 'Non-residential respite' refers to any respite activity that does not involve a service user staying overnight in a residential facility. The paper is based on research carried out in one northern city in England on behalf of the local Clinical Commissioning Group (CCG) responsible for commissioning respite services for adults with an intellectual disability and/or autism with moderate to complex needs in the city. In the city, all adults with an intellectual disability and/or autism in receipt of support from Adult Social Care (i.e. the local authority) are able to access respite should they desire. A family who has expressed a requirement for respite through their Needs Assessment work with a Care Manager to arrange the most appropriate respite, which is then funded by Adult Social Care or the local National Health Service (NHS) trust. Alternatively, following the assessment phase, carers can choose to arrange and manage the cost of respite themselves through a 'Personal Budget'. A range of 'non-residential' activities are available in the city as respite, including one-off breaks, holidays, days out, leisure activities, and a Shared Lives scheme, many of which overlap with support packages designed for service users. However, the vast majority of respite in the city is overnight stays in local authority, NHS or third party managed residential facilities. In the context of an ever growing number of service users, coupled with austerity budget cuts, the CCG were concerned that local capacity could not sustain such patterns of respite service utilisation and were keen to identify modes of prompting more equal usage of 'residential' and 'non-residential' respite by current and future service users.

The paper begins by summarising the more general barriers to respite described in the published research literature, which illuminates and contextualises the barriers to availing non-residential respite. Whilst this paper is principally about the experience of adult service users, published literature concerning children or young people with an intellectual disability and/or autism as respite service users is included in the literature review. This is because, representing a significant proportion of knowledge about respite, these papers help to illuminate potential barriers for availing respite more generally. Equally, whilst this paper is ostensibly about availing non-residential respite in the context of one northern city in England, it was felt that published international research literature would also serve to illuminate some potential barriers. Following the literature review the methodological approach adopted for this research is outlined, including how data was collected and analysed. The findings are then presented and discussed in relation to the identified research literature before the limitations of the research, areas of future exploration, and conclusions are outlined.

General barriers to respite

No research identified for this review has specifically examined the perceived or actual barriers to availing non-residential respite. However, that parents, carers and service users may face a number of barriers preventing them availing respite services in general is a clear theme in the identified literature. Power (2009:97) describes an ‘implementation gap’ between political rhetoric regarding service provision and largely “cosmetic on the ground” services. This has created a scenario where carers felt services

were lacking in both availability and quality (Power, 2009), and that service providers frequently failed to understand carers' reticence to avail themselves of services that might be of value (Mansell and Wilson, 2010).

Lack of information

The availability of useful information is vital to the sustainability of families as carers (Redmond and Richardson, 2003). Yet arguably the most significant barrier to availing respite concerns the difficulty of accessing relevant and comprehensive information about available respite services (Cotterill et al., 1997; Redmond and Richardson, 2003; Wilkie and Barr, 2008). Mansell and Wilson (2009) describe a lack of a clear and shared understanding of 'respite' between carers and social care professionals. For example, they suggest confusion as to whether an overnight stay was required for a service to be considered respite or whether a break during the day was sufficient. The general view among carers was respite required some overnight element to enable them to relax sufficiently (Mansell and Wilson, 2009). Carers felt that services would not meet their needs until there is a shared understanding of respite (Mansell and Wilson, 2009).

The process of gaining information can be haphazard, with carers often referred to speak to different officials and receiving conflicting information (Redmond and Richardson, 2003; Power, 2009). Carers may instead rely on informal networks, including friends, family, other contacts and the internet (Redmond and Richardson, 2003; Wodehouse and McGill, 2009). Research by both Redmond and Richardson (2003) and Truesdale-Kennedy et al. (2006) suggests that dedicated services may be an effective

method for providing carers with information, advocacy and support to avail essential services, including respite. However, the apparent information deficit may be a “smokescreen” to cover the gap between the aims of ambitious political programmes and limited resources to fund them properly (Power, 2009: :94).

Eligibility

Perceived or actual restrictive eligibility criteria can prevent service users and carers availing respite (Cotterill et al., 1997; Redmond and Richardson, 2003). The most prominent example of not ‘fitting’ inclusion criteria relates to challenging behaviour (McGill et al., 2006), with carers of people exhibiting serious challenging behaviour very often not receiving adequate support (McConkey, 2005). Age may also be a factor (Redmond and Richardson, 2003), with some services, including respite, only available to service users of a given age. Where service users are excluded from respite, Redmond and Richardson (2003) describe carers either having to purchase appropriate respite services themselves or go without.

Time and location

Physical and temporal barriers to respite appear to limit carers availing of services. A lack of “regular, reliable and continuous support” is described in published literature (Wilkie and Barr, 2008; Wodehouse and McGill, 2009: :651). For example, respite offered during the day was inappropriate when service users already attend a regularly scheduled event (McGill et al., 2006; Wilkie and Barr, 2008).

With regard to location, respite delivered locally is highly valued by carers (Cotterill et al., 1997; Redmond and Richardson, 2003; Wilkie and Barr, 2008). Although most carers face difficulties relating to the availability of appropriate services in their local area, a dearth of local services is most keenly felt in rural areas (Redmond and Richardson, 2003).

Administration/bureaucracy

Administrative delays and excessive bureaucracy in the organisation of respite adds to the strain of caring for someone with an intellectual disability and/or autism, and provides a barrier to accessing services, including respite (Redmond and Richardson, 2003). For example, Mansell and Wilson (2009) describe carers experiencing long waits to receive services, including respite, even after their entitlement had been recognised. Moreover, carers reported that once in receipt of respite, their provision did not change over time to reflect their changing circumstances (Mansell and Wilson, 2009).

Supportive and understanding attitudes from providers and flexibility in delivery are crucial in meeting service users' requirements (Power, 2009). The provision of appropriate respite to families requires a judgement by health professionals (McConkey et al., 2011a). However, it is not only carers and service users who struggle to negotiate respite care systems. McConkey et al. (2011a) identified a lack of familiarity among service planners with what respite services were available for carers and service users. Additionally, a lack of clarity about responsibilities can be inherent in the organisational structures of respite service providers (Redmond and Richardson, 2003).

Guilt and worry

Feelings of guilt, embarrassment and increased stress can prevent carers from utilising respite (Cotterill et al., 1997; Hartrey and Wells, 2003; Wilkie and Barr, 2008). Redmond and Richardson (2003) report mothers feeling a strain or worry when their child was in an environment with children with different needs. Other carers worry their use of respite indicates an inability to cope (Mac Donald et al., 2007).

Negative emotions associated with respite often ease after a short period of time (Wilkie and Barr, 2008). Feeling happy and confident in a respite service allays carers' feelings of guilt and anxiety, enabling carers to benefit more from the break (Cotterill et al., 1997). Reducing the stress associated with respite also occurs by having regular respite in the carer's home and establishing a long-term relationship with a particular respite carer (Hartrey and Wells, 2003).

Inappropriate venue/staff/service

Carer perception of the appropriateness of respite provision may play a crucial role in determining whether or not families avail of that service (Mac Donald et al., 2007; Nankervis et al., 2011), with carers likely to experience anxiety about the perceived quality, suitability and reliability of the service on offer (Cotterill et al., 1997; Wodehouse and McGill, 2009). Carers require confirmation that respite services will maintain the dignity of the service user (Mac Donald et al., 2007). Particular issues concerned unskilled staff and/or a lack of rapport (Wilkie and Barr, 2008) and inadequate or inappropriate facilities (Caples and Sweeney, 2011). A perception of inappropriate facilities and staff was generally most keenly felt by those with specific

medical needs or challenging behaviour. It may be good practise for respite service providers to forge trusting relationships with parents through personal contact and emotional support in addition to informational and tangible support (McConkey et al., 2011a).

Personal characteristics

Availing of respite services may relate to the personal characteristics of carers. Single parents and parents who are considered by service providers to be 'stressed' may be more likely to receive the services they need, including respite (Mansell and Wilson, 2009). Equally, carers who are tenacious in their pursuit of services and more articulate middle-class families with financial and psychological resources may be more likely to succeed in accessing appropriate respite (McGill et al., 2006). Northway et al. (2006) suggest that carers who 'shout the loudest' are the most likely to receive respite at the expense of those unable to articulate their need.

Cultural and religious barriers

Carers from ethnic minority backgrounds are more likely to underuse community care and respite services compared to other ethnic groups (Dura-Vila and Hodes, 2009; McGrother et al., 2002). Indeed, in their study of service utilisation among parents of children attending four special educational needs schools in England, Dura-Vila and Hodes (2009) identify ethnicity as the only variable to show a significant correlation with respite and other service usage.

McGrother et al. (2002) suggests a myth exists that people from minority ethnic communities have lower levels of need for respite services. In reality, carers from minority ethnic backgrounds are less likely to be aware of respite services and are more likely to encounter additional barriers preventing them availing of services. Social, cultural and religious values and beliefs about the cause and concept of 'intellectual disability' may result in the underutilisation of respite (McGrother et al., 2002). Concerns can also exist about a lack of culturally appropriate diet, facilities for washing and purifying, and language needs within respite services (Cotterill et al., 1997; Dura-Vila and Hodes, 2009; McGrother et al., 2002). Respite service planning and provision in England, may have been made – consciously or unconsciously – in accordance with 'white' norms, with a lack of accessible information and knowledge sharing with minority ethnic communities (Cotterill et al., 1997). As a result, if anything, carers from minority ethnic backgrounds may be more inclined to express a need for family-based respite (Cotterill et al., 1997).

Methods

Before commencing the research ethical approval was gained through Leeds Beckett University's internal ethics procedure. The proposal was reviewed favourably by the Local Research Ethics Coordinator in the School of Health and Wellbeing.

The research sought to gain a '360 degree' view of the perceived or actual barriers to availing non-residential respite for people with an intellectual disability and/or autism with moderate to complex needs in a northern city in England. Drawing on qualitative

and quantitative data in a mixed methods design allowed a rich understanding of carers and stakeholders lived experience to be triangulated against an overarching perspective, producing more substantive learning (Cresswell and Plano-Clark, 2011).

A bespoke postal survey was used to explore carers' awareness of respite services in the city and the appeal of, and barriers to, non-residential respite. This approach enabled a large number of carers to add their 'voice' to the project and provided an overarching perspective (Bryman, 2012) of carers' understanding and perception of respite in the city. The survey was kept to two A4 pages in length to encourage response rates.

The definitions of 'residential' and 'non-residential' respite described above were included at the beginning of the survey. The survey then consisted of five closed questions and one open question about respite service utilisation and perceptions of non-residential respite. A further seven closed demographic questions were included at the end of the survey. The survey was sent to the carers of all registered respite service users in the city (n=393) and 32% returned a completed survey (n=127). A breakdown of respondents is presented in Table 1.

Question	Available responses	Percentage of respondents
How old are you in years?	Less than 31	0
	31-40	1
	41-50	11.2
	51-60	31.2
	61-70	36.8
	71+	16

	Prefer not to say/Did Not Answer (DNA)	4
Do you care for more than one adult who is eligible for respite care?	Yes No Prefer not to say/DNA	15 82.7 2.4
How old is the person (people) that you care for in years?	18-20 21-30 31-40 41-50 51-60 61+ Prefer not to say/DNA	9.4 24.7 19.7 30.7 11.8 2.4 1.6
How much care and support would you say this person needs? (If more than one person, how much care and support do you feel you provide overall?)	Very little care and support Some of the time Most of the time Constant care and support Prefer not to say/DNA	0 8.7 25.2 64.6 1.6
How is caring responsibility divided?	I am the sole/primary carer Caring is shared with another person in the same household Caring is shared with another person outside the household Prefer not to say/DNA	49.6 42.5 6.3 1.6
How would you describe your ethnicity?	White British Asian or Asian British (Indian) Asian or Asian British (Pakistani) Asian or Asian British (Bangladeshi) Asian or Asian British (Chinese) Black or Black British Mixed or multiple Other ethnic group Prefer not to say/DNA	85.8 0 2.4 0.8 0 2.4 0.8 2.4 5.5
What is your highest academic qualification?	No academic qualifications GCSE or O Levels Practical qualifications	31.5 22 11

	A Levels	4.7
	Foundation degree	1.6
	Undergraduate degree	7.1
	Postgraduate qualification	4.7
	Prefer not to say/DNA	17.3

Table 1 Respondents and sample features

Semi-structured interviews complemented the survey data by illuminating the ‘lived experience’ (Savin-Baden and Major, 2013) of the barriers to availing non-residential respite. Due to difficulties recruiting, only fifteen interviews were conducted, including seven with carers of respite service users (CA) and eight with relevant stakeholders (ST) from Adult Social Care, Care Management Teams and third sector organisations in the city.

Carers initially volunteered to be interviewed at the end of the carer’s survey. A random sample was then approached to take part. Stakeholders were purposively sampled by the project team based on their relevance to the project aims and objectives.

Interviewees were asked about their understanding of respite in the city, experiences of barriers to non-residential respite, and how respite could be improved. All interviews were audio recorded. Two stakeholders unable to be interviewed face-to-face or over the telephone responded via email.

Quantitative data derived from the carer’s survey was transferred to the computer programme Statistical Package for Social Sciences (SPSS). From there data was subject to appropriate descriptive statistical techniques. Interviews were analysed following a

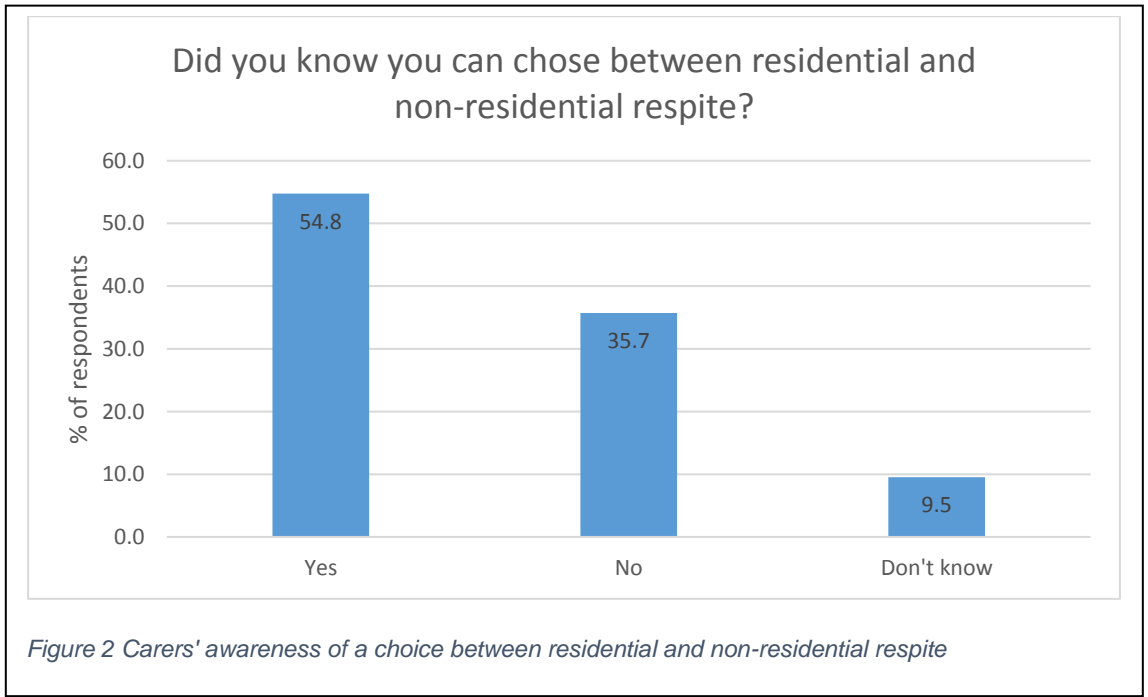
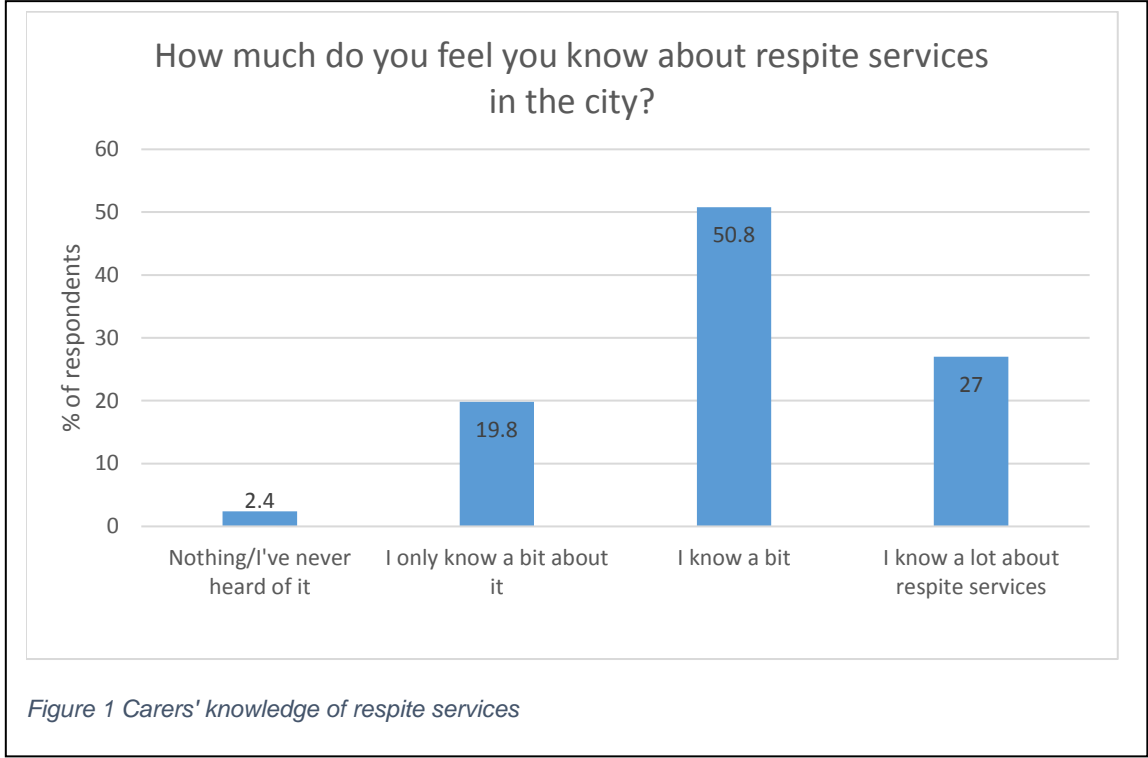
reflexive, iterative process. A common data extraction framework was devised based on key concepts pertinent to the projects primary objectives and populated with extracts from each interview. The principal investigator and a research assistant analysed the interview data independently before coming together to corroborate their interpretations. Results were then brought together and written up together.

Interim findings from the carers' survey and semi-structured interviews was presented to the city's Learning Disability People's Parliament. The meeting was attended by around fifty people, including people with an intellectual disability (N≈38), advocates (N≈7), and other presenters (N≈5). The majority of people with an intellectual disability in attendance were current or ex- respite service users. Attendees were asked three specific questions: 'what is respite?', 'why don't people like non-residential respite?' and 'what should change in the future?'. They worked in groups to discuss each question and record their answers on a large piece of paper as well as share their thoughts with the whole group. After the event, similar written responses were grouped together by the researcher. Written and verbal feedback gathered during the consultation served to corroborate and enhance the researcher's interpretation of data. Whilst direct quotes are not taken from the consultation event, the experience enriched the researchers understanding of the issues and enabled service user 'voice' to be recognised.

Findings

Awareness of non-residential respite

Previous research suggests a lack of knowledge and awareness of respite services among carers (Cotterill et al., 1997; Redmond and Richardson, 2003; Wilkie and Barr, 2008). The situation among carers in this study appears to be mixed. 27% respondents to the carers survey indicated they knew 'a lot about respite services' in the city, whilst 50.8% 'know a bit', 19.8% 'only a bit', and 2.4% indicated they knew 'nothing/have never heard of respite' (Figure 1). There is no defined distinction between the four response categories here. Rather the four point scale gives a general indication as to how much respondents subjectively feel they know about respite services in the city. The data indicates that, in general, respondents felt they were somewhat informed about respite services in the city. Just over half of respondents (54.8%) knew they had a choice between residential and non-residential respite, whilst roughly a third (35.7%) did not (Figure 2).



Seeming to reflect the apparent awareness of different respite services in the city, some interviewees recognised that “a break from caring” (ST4) could be achieved through non-residential activities. One stakeholder described the “creative...things people do and call it respite” (ST5). However, the qualitative data generally indicated the “default position” (ST3) for most carers, service users and stakeholders was to conceptualise ‘respite’ in the traditional residential form. Non-residential activities were not generally considered to be respite; “it would be [the service users] social needs being met...not their respite needs” (ST3).

Perceptions of respite provision in the city

The carers and service users spoken to generally thought the respite provision in the city was “very good”, with most carers “quite happy with how things are going” (CA3).

Carers, service users and stakeholders had some grievances about the respite services in the city, such as the limited number of hours on offer. Carers of people with complex autism, challenging behaviour and/or complex medical needs particularly felt the service was not able to meet the requirements of the person they care for. The positivity expressed towards respite services in the city appears to be specifically directed at residential rather than non-residential respite services on offer.

Residential respite was described as “essential” (ST1), a “lifeline” (ST1) and “a God send” (CA3) for carers. A number of factors contribute to the importance of residential respite. Whilst it was not the aim of this research to explore the benefits of respite for carers

and service users, it is worth documenting here those factors that were clearly articulated by carers, service users and stakeholders.

Residential respite can provide carers with a “break” (CA1) from the otherwise “24 hour responsibility” (CA2) of caring. It enables carers and service users to have some free time to do things that they want to do, including “very ordinary things” (ST4) like going to the supermarket. In doing so, residential respite can provide an opportunity for carers to spend time with other family members and to do “things that are difficult when you are caring” (ST4).

“Usually it’s just nice to relax at home’ when [son] is in respite. [Son] talks a lot – it’s just nice to sit down with everybody else and not have to think. Not to be on guard all the time... We often sleep better... That I don’t have to get up – it’s such a treat” (CA5).

Family units “take a hard knock” (CA5) caring for an adult with an intellectual disability and/or autism and residential respite relieves “a great deal of...stress” (ST1) within families.

Residential respite was well regarded by carers because it is a suitable environment for the person that they care for. For most carers, residential respite facilities were regarded as “very well equipped”, capable of dealing with service users’ complex needs and “challenging behaviour” (CA5).

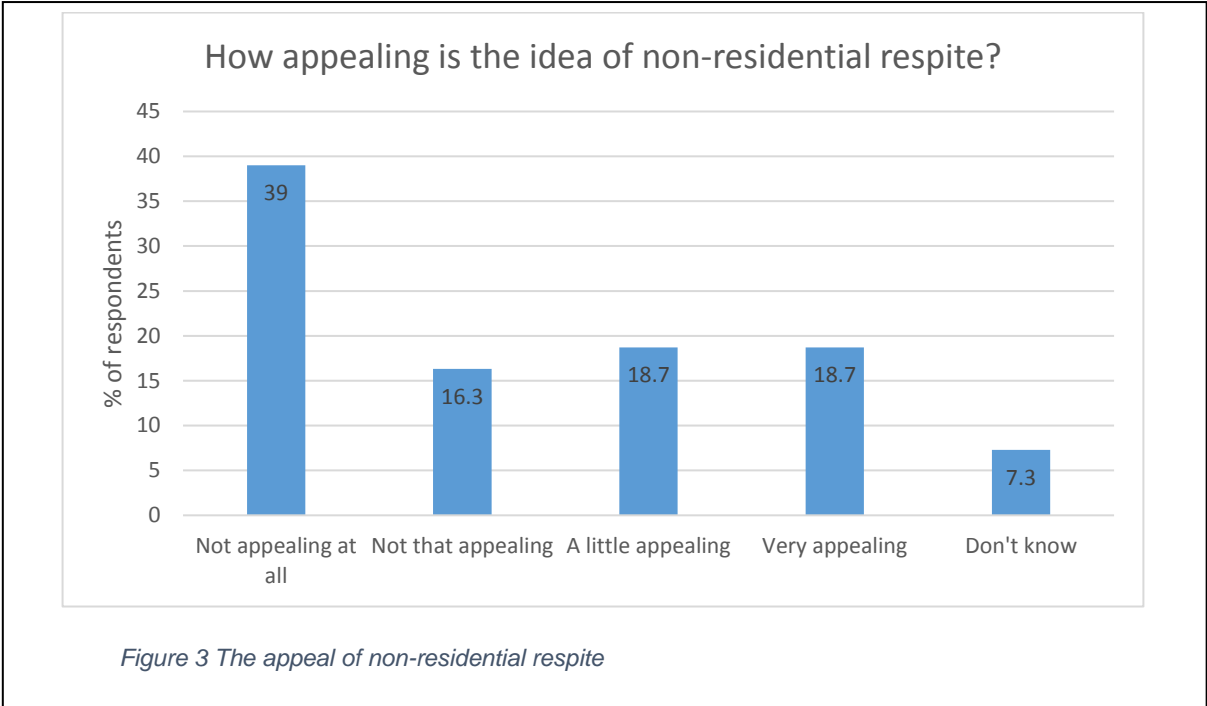
Residential respite was also felt to benefit service users, providing an opportunity to have a “holiday away from their carers” (ST1) and experience being in a different setting. Residential respite was thought of as “quite a social thing” (ST5), enabling service users to engage with their peers. Carers in the city often try and arrange residential respite at times when the same service users will be attending in order to build up continuity for the people they care for. Residential respite also includes a chance for service users to do activities they otherwise would not.

“If I’m at home with him on my own, I might think, ‘I just can’t be bothered today. And if you’re happy sitting there watching television or playing with something and doing something himself, I’m quite happy to do that today, because I haven’t got the energy to take you out’...” (ST4)

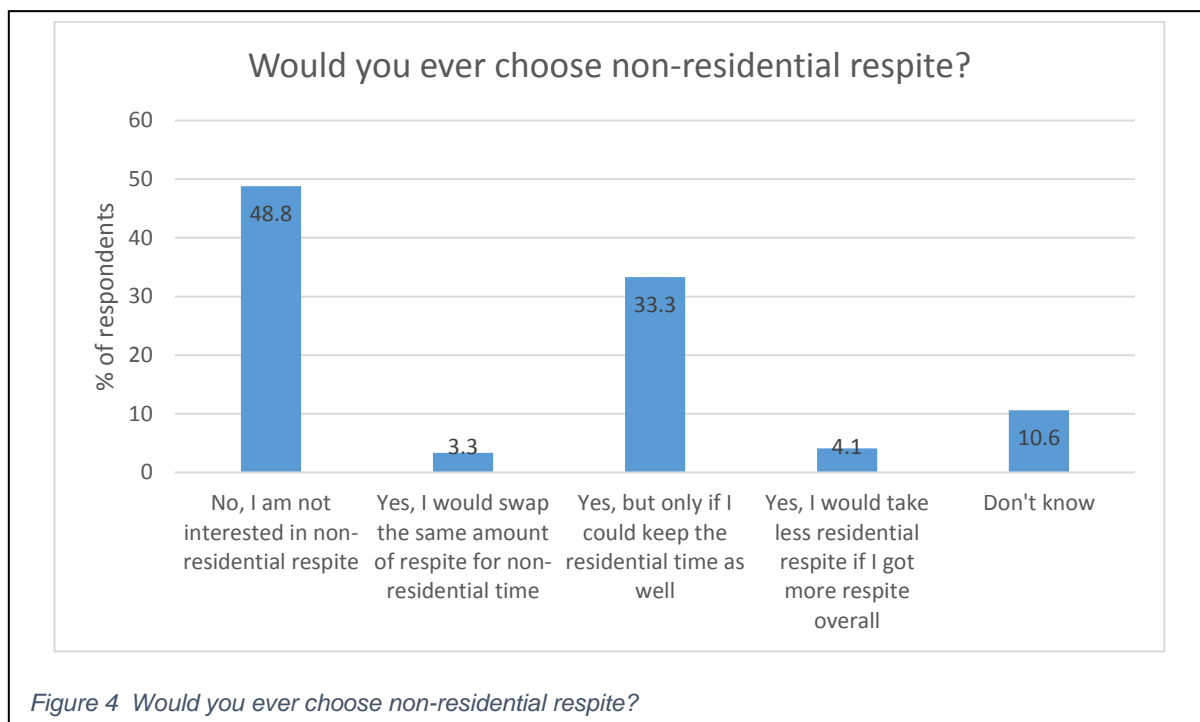
Whilst service users can be “overprotected” in their family environment (ST2), residential respite allows service users to take risks and try new things. Residential respite challenges service users to adapt to being around other people in a new social and domestic environment. Crucially, it gives service users a “taste of supported living” (CA4), which was particularly important to carers concerned about planning for the future when they are no longer able to continue in their caring role.

“It’s about teaching him independence and about him learning to live a different life away from us as well. Because we’ve always recognised that at some point [son] is going to need full time residential care” (CA5).

Non-residential respite was not viewed as positively and did not have the same appeal as residential respite. A combined 55.3% of respondents to the carers survey indicated non-residential respite was not appealing to them, with 39% stating that non-residential respite was ‘not appealing at all’ (Figure 3).



Almost half (48.8%) of survey respondents would not consider non-residential respite (Figure 4). Most of those who would considered non-residential respite (33.3%) would only do so in addition to their current residential provision. This suggests that non-residential respite may currently only be appealing as an adjunct to residential provisions.



Interview data suggests that non-residential respite may be appealing to carers in enabling service users to go on holiday, particularly with friends or “somebody that [they] know” (CA4). Whilst some carers have been able to facilitate service users going on holiday themselves, the experience can be troublesome. For example, the cared-for person may get bored and want to do different activities to their carers.

‘We’re fuddy-duddies for him now. He doesn’t mind doing some things with us, but he likes to do things with other people.’ (CA5).

Using respite time to allow service users to go on holiday was welcomed; “instead of just going to a home they might be able to go on a holiday” (CA4). Holidays without the carer provide a very different kind of respite than other non-residential services, and are

much closer to residential respite in terms of duration and location (i.e. an extended time spent away from 'home'). Although there are options available in the city to enable a cared for person to "go on holiday for the first time" (ST2) (i.e. Shared Lives, Direct Payments), carers appeared not to be aware of these in great numbers.

Perceived or actual barriers to non-residential respite

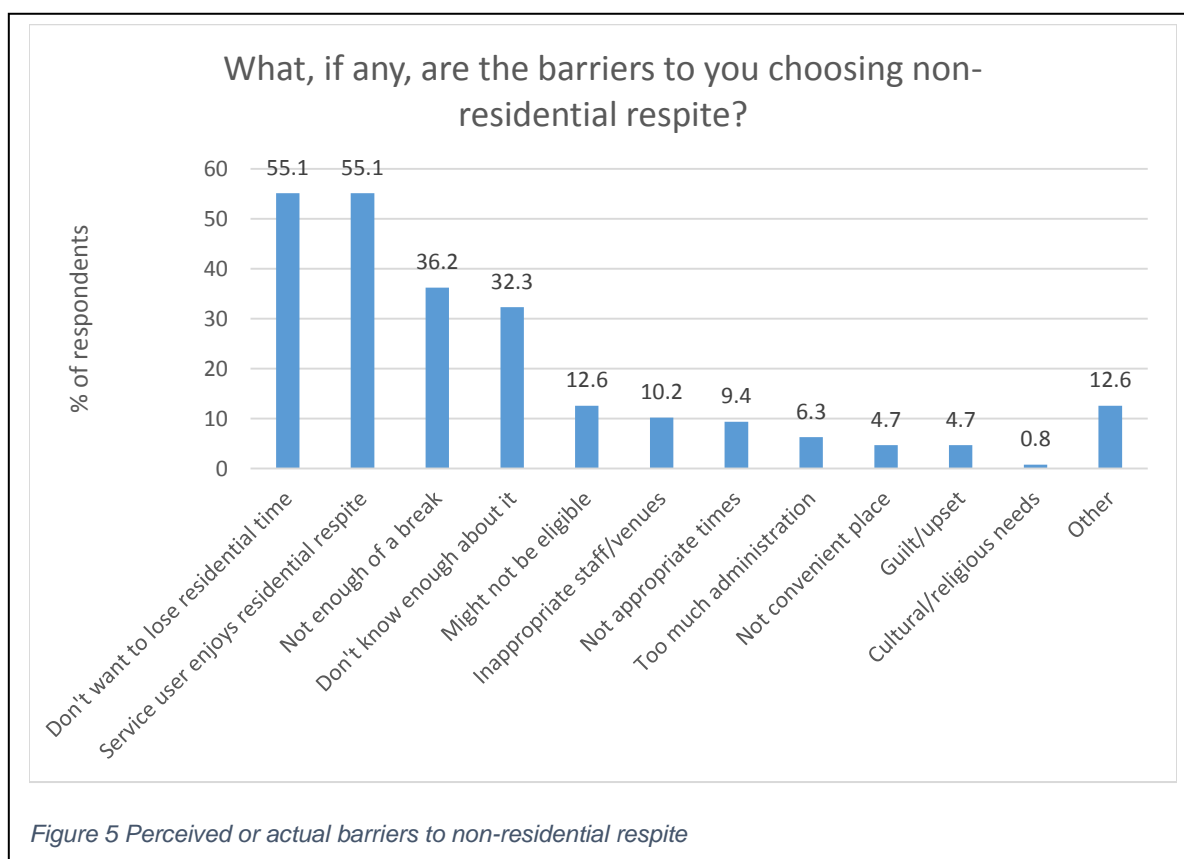
A number of perceived or actual barriers to carers availing non-residential respite were observed in the carers survey (Figure 5) and reinforced in the qualitative data.

55.1% of respondents indicated a fear of losing their current residential respite allocation. As highlighted previously, residential respite is highly valued by carers and the thought of not having it is extremely troubling for carers.

An equally significant barrier was that service users enjoy residential respite; 55.1% of respondents reported this was the case. One questionnaire respondents said "my daughter loves her stay at residential and treats it as a holiday". Participants at the consultation event with current and ex- respite service users also said that attending residential respite could be an enjoyable activity. There may be a danger, however, of services users' preferences for particular services (i.e. residential respite over non-residential) having a detrimental effect on carers, preventing them availing the most appropriate services to support them in their caring role.

"Sometimes the barrier is the cared for person not wanting to accept the support that the carer would like - doesn't like the look of the place, the look of

the people, or just thinks ‘I want you to do everything for me’. That can be a barrier” (ST4).



Just over a third of survey respondents (36.2%) felt that non-residential respite would not provide them enough of a break from their caring responsibilities. Whilst residential respite provides a “proper break” (Q) from caring responsibilities, carers felt non-residential respite would not allow them to “get away completely” (CA4), physically and emotionally. This view was shared by current and ex-service users who suggested

residential respite was an opportunity for them to have a break from their parents/carers.

32.3% of respondents felt that a lack of information was a barrier to them availing non-residential respite. Accessing information about respite services in the city was described as “really difficult” (ST4) for carers. Carers felt there was “not enough” (CA1) information available and the little information available is “dotted around” (CA1) different locations. As such, carers “don’t know what to do and how to access [different respite services]” (ST3). Current and ex-service users felt they did not know enough about non-residential respite but may be open to trialling non-residential respite given more information.

Carers rely on care professionals to help them make sense of their options regarding respite services. However, there remains “a lot of ignorance” (ST5) among care professionals in the city regarding different respite services; many “probably don’t know enough about any non-residential respite” (ST7) and are not aware that respite has “more to offer than buildings based” residential respite (ST2). As such, residential respite dominates the offer. Many carers also rely on informal networks or word-of-mouth for information regarding respite; “other people in a similar situation...are the best people to find out things from” (ST4). It appears that the experience of other families can be very powerful in shaping service utilisation by both creating and dispelling misconceptions about respite services in the city.

More information about different respite services may be beneficial in helping carers and service users make more informed decisions. Carers and service users need information that is “really clear...something that spells out what is available” (ST4), including examples of what different people do and the combination of provisions that are possible.

“To be able to go to and say ‘this organisation does it this way and that little group does it that way, it’s not just the six buildings around the city’” (ST3).

An accessible “menu” (ST2) of provision would enable carers and service users to make informed choices about respite. This may involve working closely with third party providers to publicise non-residential respite. A “flow chart” (ST2) of different respite options may also help Care Managers see beyond ‘traditional’ residential respite. The option to trial different respite services may also facilitate carers and service users to utilise provisions other than traditional residential respite. Currently there appears to be a lot of confusion and apprehension about non-residential respite.

12.6% of carers’ survey respondents reported not knowing if they were eligible for non-residential respite. In accordance with the identified research literature, age is a significant factor with regard to perceived eligibility. Carers felt that their choice of a different respite services “disappear[ed] off the radar” (CA2) once service users reached adulthood. One stakeholder suggested non-residential respite “feels like something for a younger service user” (ST3). Perceived eligibility also extends to how well a family is judged to be coping in their caring role. That is to say, families not in ‘crisis’ – “if you’re

classed as a competent family” (CA5) – may be thought to need less support from care professionals and therefore be less able to access different services, including non-residential respite.

For just over a tenth of survey respondents (10.2%), concerns that staff or venues for non-residential respite will be inappropriate for service users is a barrier.

“As a carer you have to feel that the provision is good in order for you to relax and enjoy that time away from caring.’ If you think the person is not going to be happy then you’re not going to take it up other than in an emergency” (ST4).

Concerns include: staff at non-residential respite being less competent, including a “lack of specialist medical knowledge” (Q), and less reliable than those in residential settings; service users being cared for in non-residential respite alongside other service users whose medical, behaviour and social needs are either too similar or too diverse; and non-residential respite being ‘unsafe’ compared to residential respite, which is perceived as having “more safeguards in place” and “proper routines [and] regulations” (CA5). Concerns about inappropriate staff and venues are exacerbated for carers of adults with more complex health needs, challenging behaviour and autism.

“When it comes to autistic people, you need someone with a good knowledge of the actual person and a good knowledge of autism... There has to be a good understanding of this complex condition. What might fit one person, won’t fit another” (CA7).

Comparatively, residential respite is viewed “like a really good hotel” that understands the complexity of service users (ST3).

Non-residential respite is also viewed by carers as unreliable; support workers may be unavailable for such a short time or move on to other roles. For carers are concerned about longer term consistency in the services they receive, residential respite settings “feel more stable” (ST4).

9.4% of respondents reported non-residential respite not being at appropriate times as a barrier. Carers want the flexibility to avail respite when it suits their needs. For example, some carers want to have respite at weekends, whilst others like to spend that time with the person they care for – “she goes away through the day anyway, why bother having it at weekend as well” (CA3). However, carers perceived non-residential respite as being very inflexible and only during weekdays.

6.3% of respondents suggested that accessing non-residential respite involved too much administration and/or bureaucracy. Baring in mind the qualitative data, this has been interpreted to mean availing non-residential respite involves too much administration and/or bureaucracy for carers already “used to residential services” (ST7). For carers already stretched by their caring responsibilities, availing non-residential respite equates to “somebody else to have to meet with, something else to have to organise” (ST4). It’s simpler to think “my life’s complicated already, I’m not going there” (ST4) and remaining just with residential respite. Additional administration and/bureaucracy can also be a barrier to care professionals, particularly for Care Managers who liaise with carers. In

the “fast, furious life of a Care Manager, [needing] results quickly...to move onto the next situation,” (ST2) the time and effort to discuss and arrange anything other than residential respite is a disincentive to promoting non-residential respite to carers. A lack of time to facilitate non-residential respite was described as a “structural” barrier (ST2).

Direct Payments were described by stakeholders as an opportunity for carers to be “creative” (ST5) with the services they access, including “more flexibility in how they want their respite to be provided” (ST3). The perception of Direct Payments among carers, however, was generally negative. One carer said their use of Direct Payments in the past was “one of the worst things that ever happened” to their household (CA2).

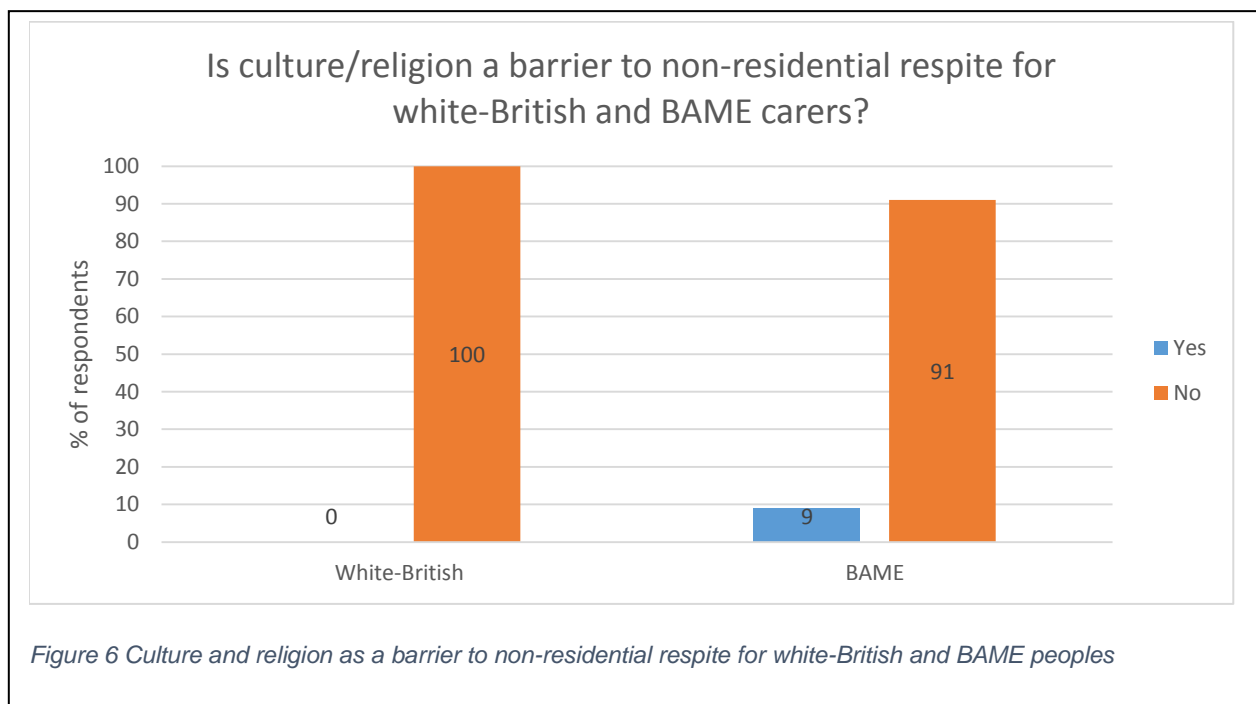
Direct Payments were criticised for being “too complicated” (ST2) and creating more work for carers. Utilising Direct Payments was viewed as “doing [the City Council’s] work for them” (CA2). Whilst carers want a choice regarding respite, they “have got enough on their plate” (ST2) coping with the caring responsibilities to deal with the extra effort required to utilise personalised provision this way.

4.7% of respondents reported non-residential respite not being in a convenient place as a barrier. One survey respondent stated that non-residential respite would be more appealing “if it was somewhere local to where we lived” (Q). Another carer did not want the person they care for attending non-residential respite because they thought it would take place in what they perceived as “very nasty little area[s]” of the city (CA7).

4.7% of respondents reported that feelings of guilt or upset caused a barrier. Mirroring the identified literature, accessing respite can cause carers to feel guilty and anxious

that they have “failed” in their caring role (ST4) or that they “always should be there for the child with disability” (CA5). As such, utilising non-residential respite, which may involve less than a day’s activity, was thought to be “not worth the upset for the short time you receive” (Q). Moreover, some forms of non-residential respite, such as community-based care, may exacerbate negative emotions because of a view that “if that family can cope...why can’t I?” (ST2).

Only 0.8% of respondents indicated a concern that non-residential respite would not meet their cultural or religious needs as a barrier. A comparison between respondents from white-British and Black, Asian and minority ethnic (BAME) backgrounds (Figure 6) suggests cultural or religious differences are not a significant barrier to carers from BAME backgrounds in the city. Although this contradicts the assertion of the identified published literature, the findings may be a response bias as a result of the limited number (n=11) of survey respondents from BAME communities.



12.6% of respondents suggested an ‘other’ barrier prevented them from availing non-residential respite. Carers may feel their non-residential respite need has already been fulfilled, either through purchasing additional support from “outside agencies” (Q) or because the person they care for attends other scheduled activities. The human capital of carers – their knowledge, skills and capacities – was alluded to as a barrier to availing non-bed-based respite. One stakeholder suggested how “creative” (i.e. how personalised to the needs of service users and families) respite is depends on “the demanding nature of the family” and that “some families are better [at availing personalised services] than others”. Carers were also concerned that non-residential respite would be prohibitively expensive. Finally, non-residential respite may breach the

privacy of carers and their families; “being able to trust people in your home” (Q) is a barrier.

“You can have respite in your own home. If you wanted to go on holiday ... somebody would come into your home and work there 24 hours a day. The issue with that is not a lot of people take that up because it’s someone coming into your home that you don’t know and you’re not there” (ST5).

Discussion

Respite services enable carers of people with an intellectual disability and/or autism to benefit from taking a break from their caring responsibilities. Respite can also benefit service users, enabling them to take a break from the family setting, socialise with peers, and build independence. This paper is based on research carried out in a northern city in England where a potentially unsustainable proportion of respite service users utilise ‘residential’ respite. The aim of the paper has been to understand the actual or perceived barriers to availing ‘non-residential’ respite for adults with an intellectual disability and/or autism with moderate to complex needs in the city.

A literature review revealed a number of barriers to availing respite in general, some of which have relevance with regard to barriers experienced by carers of people with an intellectual disability and/or autism availing of non-residential respite. Previous research has found that carers experience difficulties accessing relevant and comprehensive information about respite services (Cotterill et al., 1997; Redmond and Richardson, 2003; Wilkie and Barr, 2008). This is slightly at odds with the survey data from this study

which suggested most carers are aware of a range of different respite options and of a choice between residential and non-residential respite. However, exploring these findings in more detail through qualitative interviews with carers and stakeholders revealed that, despite an apparent awareness of the range of respite provisions, as described by Wilkie and Barr (2008) and McConkey et al. (2011b), the 'default position' for most carers, stakeholders and service users in the city was that respite is a residential activity.

Concerns about eligibility were a barrier to availing non-residential respite for carers in this study. As with the findings of McGill et al. (2006) and McConkey (2005), there was a concern that service users exhibiting challenging behaviour would not be entitled to non-residential respite. Carers also expressed concerns that the person they cared for might be the wrong age for non-residential respite. Whilst age has been identified as a barrier to people with an intellectual disability and/or autism accessing support services, including respite, elsewhere (Redmond and Richardson, 2003), in this instance there is no actual exclusion criteria to availing non-residential respite based on age. Rather, carers perceived non-residential respite activities as being more appropriate for younger service users.

Location and timing was a barrier to availing non-residential respite as it has been found to be with regard to availing of respite more generally. Similar to the findings of McGill et al. (2006) and Wilkie and Barr (2008), non-residential respite offered during the day was not appealing when service users already had something scheduled. Carers wanted

non-residential respite delivered locally (Cotterill et al., 1997; Redmond and Richardson, 2003; Wilkie and Barr, 2008) and were concerned that what was on offer would not be conveniently located and not in 'nice' areas.

As in the identified literature (i.e. Mansell and Wilson, 2009; Redmond and Richardson, 2003), a concern that availing non-residential respite would entail additional administration and drawn-out bureaucratic procedures was a prominent barrier. Carers already felt the strain from their caring responsibilities and anything they felt would add to, rather than alleviate, their burdens was not viewed positively. This also included Direct Payments which, despite being a proposed route to greater individualisation of services (Caldwell, 2007; Redmond and Richardson, 2003), including non-residential respite where appropriate, was not welcomed by the carers involved here. Moreover, the potential additional burden of availing non-residential respite instead of the more familiar residential form was also felt by Care Managers struggling to cope with their existing workloads. As such, rather than encouraging carers and service users to explore potentially beneficial alternatives, they were happy for service users to continue to follow the path most trodden with residential respite.

Feelings of guilt and worry was a barrier for some availing of non-residential respite just as it has been for others availing respite in general (Cotterill et al., 1997; Hartrey and Wells, 2003; Wilkie and Barr, 2008). Additionally, non-residential respite may heighten feeling of 'If they can cope, why can't I?' as the service users is potentially supported by another family or person in the community rather than in a residential facility staffed by

‘professionals’. Whilst the negative emotions associated with residential respite often ease with time (Wilkie and Barr, 2008), a short spell of non-residential respite may not be long enough for negative feelings to dissipate.

Carers have previously been shown to be concerned about the appropriateness of the venue and staff where the person they care for is to have respite (Cotterill et al., 1997; Wodehouse and McGill, 2009; Mac Donald et al., 2007; Nankervis et al., 2011). This appears to be a significant barrier to availing non-residential respite in particular. In comparison to residential respite, which can be viewed as a well-equipped hotel, non-residential respite was, at worst, viewed as unsafe, ill-equipped, unregulated, and manned by unreliable and unskilled staff. This concern was particularly acute for carers of people with complex medical needs and challenging behaviour.

As with availing of respite more generally (Mansell and Wilson, 2009; McGill et al., 2006; Northway et al., 2006), the personal characteristics of carers appeared to affect their ability to avail non-residential respite. Those thought to be struggling in their caring role and those who ‘shout the loudest’ were thought to be more likely to receive help from relevant authorities in accessing support, including non-residential respite. Particularly attention was drawn to the ability of articulate, middle-class families to avail more personalised services, including non-residential respite where desired.

Whilst particular emphasis in the identified research literature is given to the cultural and religious barriers that families from BAME communities may face in accessing support services, including respite (Cotterill et al., 1997; Dura-Vila and Hodes, 2009;

McGrother et al., 2002), this was not expressed by the participants involved in this research. Less than 1% of respondents – only 9% of respondents from BAME backgrounds – indicated cultural or religious needs prevented them availing non-residential respite. However, this outcome may be the result of response bias.

In addition to the barriers shared with availing respite in general, an additional barrier particularly to availing non-residential respite has been identified through this research. In comparison to residential respite where support is provided outside of the family home, it was felt that non-residential respite may breach the privacy of carers and their families by having support provided in their home. Carers need to be able to trust the respite provider with their family's privacy, something that does not occur with residential respite.

What has become clear throughout the course of this research is that residential respite is thought of as beneficial for carers and service users. Of particular importance is a belief that residential respite enables service users to prepare for a time when carers are no longer able to continue in their caring roles and of living away from home. This positive view does not extend to non-residential respite and the majority of carers would only utilise non-residential respite as an adjunct to their existing residential provision.

Most carers, where possible, want the person they care for to live a full and rich life with the opportunity to take part in varied activities and grow and develop as individuals. In principal at least, non-residential respite, as part of an individualised packaged of

support, has the potential to help achieve this aim by being tailored to the specific needs and wants of service users. For example, availing non-residential respite could be a means for service users to go on holiday independently or with friends, something carers were in favour of. However, carers of people with an intellectual disability and/or autism with moderate to complex needs experience too much pressure in their caring roles (and Care Managers have limited capacity) to experiment with new services. Traditional residential respite, in most cases, offers a tried and tested mode of relief, whereas non-residential respite is something extra to deal with. Persuading carers to give up the security that comes with residential respite in exchange for an unknown service (i.e. non-residential respite) is unlikely unless carers and service users can be reassured that they will, at the very least, not be worse off.

In the first instance, it would be beneficial for carers, service users and practitioners to be more informed about the range of respite provisions available to them. Currently there is an overlap between non-residential respite and support packages designed for service users, all of which provide some respite for carers and service users. This blurred distinction can cause confusion in the minds of carers and among service providers. A 'menu' of what is on offer, including examples of who has used the service in the past and where services can be personalised, may help dispel some misconceptions about non-residential respite and allow carers and service users to make more informed choices about the services they access. Information should be available from a central

access point and from Care Managers and be accessible to all. Work should be done collaboratively with third party providers to ensure choice.

This research does have a number of limitations meaning the findings may not be entirely generalizable. First and foremost, the research is based in one northern city in England with its own particular social, economic, and governance context. That is to say, the experience of service users, carers and service providers availing non-residential respite may be different in an alternative setting. Secondly, due to difficulties in recruitment, only a small sample of carers and stakeholders have been interviewed. Thirdly, the voice of carers and stakeholders has been prioritised in this research over that of service users themselves. This was due to the additional resources required to adequately involve people with an intellectual disability and/or autism in social research effectively, which was not available in this instance. To address these limitations, future research should explore the barriers to non-residential respite in different locations, include a larger sample of interviewees, and prioritise the voice of service users. More generally, this research can be seen to represent the first exploratory steps into a broader field. There is potential to examine each individual barrier in greater detail and to consider the experience of specific service users based on, for example, age, ethnicity, and socio-economic status. In particular, given that demand for respite services in England is only expected to increase, exploring the wants, desires and experiences of young people with an intellectual disability and/or autism and their families regarding their aspirations for respite care should be used to shape future provision.

Conclusion

The aim of this paper was to describe the actual or perceived barriers to availing non-residential respite for adults with an intellectual disability and/or autism with moderate to complex needs in one northern city in England. A mixed-method methodology was employed utilising semi-structured interviews with carers and stakeholders, a postal survey sent to carers, and a consultation event with current and ex- service users.

The evidence gathered indicates that there are a number of barriers preventing the utilisation of non-residential respite care, including a lack of information, concerns about eligibility, time and location of services, excessive administration and bureaucracy, negative emotions associated with utilising support services, potentially inappropriate venues, staff and services, cultural and religious needs, and the personal characteristics of service users and their families. Many of these barriers are shared with people with an intellectual disability and their families trying to access support services more generally. A unique barrier to availing non-residential respite compared to residential respite is carers' potentially having to trust support workers coming into their homes as opposed to the service users being supported in an external location.

Whilst non-residential respite may have a role to play as part of more individualised packages of support for people with an intellectual disability and/or autism with moderate to complex needs, non-residential respite does not necessarily provide the tried and tested mode of relief that residential respite provides for many carers and service users. More accessible information for carers, service users and stakeholders

about non-residential respite may help to dispel some misconceptions about non-residential respite and challenge the default conceptualisation of 'respite' as taking place in a residential setting, allowing carers and service users to make more informed choices about the services they access.

Acknowledgments

The author wishes to thank Dr. Leonie O'Dwyer for her hard work and effort during data collection. The author also wishes to acknowledge the support and patronage of Norman Campbell, Commissioning Manager Learning Disability & Autism, Leeds Clinical Commissioning Groups Network throughout the course of the project.

References

- Bryman A. (2012) *Social research methods*: Oxford : Oxford University Press, c2012. 4th ed.
- Caldwell J. (2007) Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program. *Disability & Society* 22: 549-562.
- Caples M and Sweeney J. (2011) Quality of life: a survey of parents of children/adults with an intellectual disability who are availing of respite care. *British Journal of Learning Disabilities* 39: 64-72.
- Cotterill L, Hayes L, Flynn M, et al. (1997) Reviewing Respite Services: some lessons from the literature. *Disability & Society* 12: 775-788.
- Cresswell J and Plano-Clark V. (2011) *Designing and Conducting Mixed Method Research*, London: Sage.
- Dura-Vila G and Hodes M. (2009) Ethnic Variation in Service Utilisation among Children with Intellectual Disability. *Journal of Intellectual Disability Research* 53: 939-948.
- Government H. (2008) *Carers at the heart of 21st-century families and communities*, London: Department of Health.
- Hartrey L and Wells JSG. (2003) The meaning of respite care to mothers of children with learning disabilities: two Irish case studies. *Journal of Psychiatric & Mental Health Nursing* 10: 335-342.
- Mac Donald E, Fitzsimons E and Walsh PN. (2007) Use of respite care and coping strategies among Irish families of children with intellectual disabilities. *British Journal of Learning Disabilities* 35: 62-68.

- Mansell I and Wilson C. (2009) Current perceptions of respite care: experiences of family and informal carers of people with a learning disability. *Journal of Intellectual Disabilities* 13: 255-267.
- Mansell IAN and Wilson C. (2010) 'It terrifies me, the thought of the future': listening to the current concerns of informal carers of people with a learning disability. *Journal of Intellectual Disabilities* 14: 21-31.
- McConkey R. (2005) 'Fair shares? Supporting families caring for adults persons with intellectual disabilities. *Journal of Intellectual Disabilities Research* 49: 600-612.
- McConkey R, Gent C and Scowcroft E. (2011a) Critical features of short break and community support services to families and disabled young people whose behaviour is severely challenging. *Journal of Intellectual Disabilities* 15: 252-268.
- McConkey R, Kelly F and Craig S. (2011b) Access to respite breaks for families who have a relative with intellectual disabilities: a national survey. *Journal of Advanced Nursing* 67: 1349-1357.
- McGill P, Papachristoforou E and Cooper V. (2006) Support for family carers of children and young people with developmental disabilities and challenging behaviour. *Child: Care, Health & Development* 32: 159-165.
- McGrother CW, Bhaumik S, Thorp CF, et al. (2002) Prevalence, morbidity and service need among South Asian and white adults with intellectual disability in Leicestershire, UK. *Journal of Intellectual Disability Research* 46: 299-309.
- McGrother CW, Hauck A, Burton PR, et al. (1993) More and better services for people with learning disabilities. *Journal Of Public Health Medicine* 15: 263.
- Nankervis K, Rosewarne A and Vassos M. (2011) Why do families relinquish care? An investigation of the factors that lead to relinquishment into out-of-home respite care. *Journal of Intellectual Disability Research* 55: 422-433.
- Northway R, Sardi I, Mansell I, et al. (2006) *Hopes and fears concerning service developments: A focus group study of parents and carers of people with a learning disability*, University of Glamorgan.
- Petr CG and Barney DD. (1991) Keeping Children with Disabilities at Home: Research Results of the Parent Perspective.
- Power A. (2009) 'It's the system working for the system': carers' experiences of learning disability services in Ireland. *Health & Social Care in the Community* 17: 92-98.
- Redmond B and Richardson V. (2003) Just Getting on with it: Exploring the Service Needs of Mothers Who Care for Young Children with Severe/Profound and Life-Threatening Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities* 16: 205.
- Savin-Baden M and Major CH. (2013) *Qualitative research : the essential guide to theory and practice*: London : Routledge, 2013.
- Truesdale-Kennedy M, McConkey R, Ferguson P, et al. (2006) An Evaluation of a Family-centred Support Service for Children with a Significant Learning Disability. *Child Care in Practice* 12: 377-390.
- Upshur CC. (1983) Developing Respite Care: A Support Service for Families with Disabled Members. *Family Relations* 32: 13.

- Wilkie B and Barr O. (2008) The experiences of parents of children with an intellectual disability who use respite care services. *Learning Disability Practice* 11: 30-36.
- Wodehouse G and McGill P. (2009) Support for family carers of children and young people with developmental disabilities and challenging behaviour: what stops it being helpful? *Journal of Intellectual Disability Research* 53: 644-653.